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August 5, 2004

Mr. Broyce Jacobs, MLA
Chair, Select Special Health Information Act Review Committee
Legislative Assembly of Alberta
801 Legislature Annex
9718 – 107th Street
Edmonton, AB T5K 1E4

Dear Mr. Jacobs,

Re: Submission to the Select Special Health Information Act Review Committee

Please accept the enclosed attachment as my submission to the Select Special Health Information Act Review Committee. The submission offers a total of ten recommendations in the following areas of the Act: seven recommendations regarding Part I – Interpretation, two recommendations regarding Part 5 - Disclosure of Health Information and one recommendation regarding Part 7, Division 3 Commissioner Powers.

I look forward to discussing my submission with the Committee and respectfully request an opportunity to provide an oral submission during your scheduled meeting day of August 25th as I will be out of the country in September when oral submissions are expected to be heard.

I trust that the recommendations will be helpful to the Committee. If any further information or clarification is required, I will be pleased to provide it during the course of the Committee's deliberations.

Yours truly,

Frank Work, Q.C.
Information and Privacy Commissioner

Submission to the Select Special Health Information Act Review Committee

By
Frank Work, Q.C.
Information and Privacy Commissioner

August 5, 2004
Edmonton, Alberta

Office of the Information and Privacy Commissioner of Alberta

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I. Message from the Commissioner

Mr. Chairman, I am pleased to make this submission as part of the three-year review of the Alberta *Health Information Act* ("HIA" or the Act).

The Act was passed by the Alberta Legislative Assembly on December 9, 1999 and came into force on April 25, 2001. The Act applies to the health sector. It covers most of the public health sector and some of the private health sector.

The Act applies to areas of the public health sector that were not previously governed by the *Freedom of Information and Protection of Privacy Act* (the "FOIP Act"). For example, the provisions governing the provincial health insurance plan, cancer programs, hospitals, organ donation, mental health, nursing homes and public health prevailed over the FOIP Act (ss. 15(1)(a) and 15(2) of an earlier version of the *Freedom of Information and Protection of Privacy Regulation* (the "FOIP Regulation"; note this provision was repealed after HIA was proclaimed).

The Act applies to activities that were not previously covered by the FOIP Act (Section 15(1)(a) of the FOIP Regulation) such as "quality assurance activities". The Act applies to "health services providers" such as physicians in physician offices and clinics when providers are paid by the AHCIP. The Act also applies to parts of the "private health sector" such as pharmacists and pharmacies.

However, the Act did not extend to all of either the public or private health sector. For example, the Act did not cover ambulance services governed by the *Confidentiality Regulation* under the *Ambulance Services Act*. The Act did not extend to the Alcohol and Drug Abuse Commission, which was governed by the *Alcohol and Drug Abuse Act* with section 8 of that Act prevailing over the FOIP Act.

The Act created more consistent obligations with respect to the health information held by custodians previously governed by disparate rules, such as regional health authorities, Alberta Health and Wellness, hospitals, cancer programs, home care programs, provincial boards, nursing homes, mental health and public health. It consequentially amended and consolidated the access and confidentiality provisions in 15 different statutes. The Act created new rights of access, correction and amendment for individuals whose health information was in the custody or control of custodians who were not previously governed by access and privacy legislation such as pharmacies, pharmacists and physician offices.

Since the Act was enacted in 1999, changes have occurred that affect health information in Alberta. PIPEDA, the federal privacy legislation, came into force in a staged manner. PIPEDA applied to all personal information involved in commercial activities, including health information, as of January 1, 2004. PIPEDA extends to personal information within provincial jurisdiction unless that information is governed by provincial legislation that has been declared by order to be substantially similar to PIPEDA.

HIA and PIPEDA both apply to health information in the private sector in Alberta such as in pharmacies. There has been no formal consideration or declaration as to whether HIA is substantially similar, but it seems generally regarded as not being substantially similar to PIPEDA. However, recent interpretations of PIPEDA such as the 'circle of care' and the consent requirements have lessened the perceived differences between HIA and PIPEDA.

It is anticipated that the "Pan Canadian Framework" will assist in harmonizing the approaches to health information legislation across Canada. The Pan Canadian framework may assist with the impending legislative review of PIPEDA and may inform the debate over the desirability of a carve out of health information from PIPEDA.

However, even if all jurisdictions agree to incorporate the general approach set out in the Pan Canadian framework, there will still be some legislative differences. For example, each jurisdiction has slightly different legislation for the age of majority and for surrogate decision-makers such as guardians, trustees, agents in personal directives, powers of attorney, personal representatives and nearest relatives.

Since the Act was proclaimed, changes have occurred in provincial legislation that affect health information. The FOIP Act has undergone its second legislative review. The Legislature has incorporated amendments such as the explicit inclusion of genetic information within the definition of "personal information" under FOIP. This should be considered under HIA.

The second FOIP review specifically recommended that consideration be given to harmonization of the FOIP Act and HIA during the three-year review of HIA. Consideration of any such amendments must keep in mind the fundamental differences between the two pieces of legislation. For example, under the FOIP Act personal information can be disclosed unless the disclosure is prohibited in the FOIP Act. In contrast, under HIA, health information can not be collected or used or disclosed except as authorized in HIA.

On January 1, 2004, private sector legislation came into force in Alberta. The *Personal Information Protection Act* ("PIPA") is parallel legislation to PIPEDA and applies to personal information except as already covered by the FOIP Act or HIA. PIPA applies to personal employee information and self governing organizations such as the colleges of the health professions. It is anticipated that PIPA will be found to be substantially similar to PIPEDA although an Order-In-Council has not yet been issued.

Neither PIPA nor HIA applies to health information that is collected, used or disclosed by a private organization for health system purposes, such as the individual health records compiled when providing private health services. This represents a gap in the provincial legislation. Currently only PIPEDA applies to that information. This means that Albertans do not have access to provincial oversight or consistent rights of access, correction and amendment or redress for breaches of privacy for their health information.

The provincial rights and protections for health information that Albertans have gained under HIA in the public sector by and large do not yet exist in the private sector. In my opinion, this issue should be addressed during this legislative review.

II. Specific Recommendations

A. Interpretation (Part 1)

HIA contains a somewhat unusual mandatory requirement that this legislative review must consider. Should the Act be amended to apply to particular additional entities? This review must consider whether HIA should apply to Government departments, local public bodies and to any other entity that is not a custodian but has information about the health of an individual in its custody or under its control (s. 109(2)). In other words, this review must consider whether these other entities should be added to the list of custodians.

HIA applies to health information in the custody or control of any entity that falls within the prescribed list of custodians in section 1(1)(f) of the Act. Custodians are the primary gatekeepers under the Act. However, persons who perform a service for custodians such as employees, students, volunteers, contractors and agents are "affiliates" (s. 1(1)(a)) and are also bound by the Act. Affiliates become secondary gatekeepers due to the HIA obligations that arise by virtue of their relationship with custodians.

1. HIA Section 1(1)(f): Maintain status quo for application to additional Government Departments and Local Public Bodies

This review must specifically address the application of HIA to the information about health that is in the custody or control of departments of the Government of Alberta (s. 109(2)(a)) and local public bodies as defined in the FOIP Act (s. 109(2)(b)).

A "public body" is defined in section 1(1)(p) of the FOIP Act and includes a department, branch or office of the Government of Alberta, an agency, board, commission, corporation, office or other body designated as a public body in the regulations and a local public body.

Some Government departments have extensive amounts of information about the health of individuals in their custody and control such as Children's Services, Community Development, Human Resources and Employment, Infrastructure, Justice and Learning. In addition to the health services these departments directly provide or fund, many of their associated entities require extensive information about health to carry out their government functions and programs.

In some instances public bodies collect the information about health directly from the individual or from another person acting on behalf of the individual. In other instances they obtain information about health indirectly from other sources such as from government departments and entities governed by the FOIP Act or from private organizations that may be governed by PIPA or PIPEDA.

In other instances, public bodies obtain information about health from HIA custodians such as regional health authorities, hospitals, nursing homes, physicians or pharmacists. The Department of Health and Wellness and the Minister of Health and Wellness are the only government departments and offices that are currently listed as custodians (ss. 1(1)(f)(xii) and (xiii)) in HIA.

A "local public body" under the FOIP Act includes an educational body, a health care body and a local government body (s. 1(1)(j)). An "educational body" is defined in section 1(1)(j) of the FOIP Act and includes universities, technical institutes, public colleges, the Banff Centre and the boards, charter schools and Regional authorities as defined in the *School Act*. Some educational bodies provide student health services. All educational bodies have some information about the health of their students and consequently health records. Some educational bodies even have specific enactments for health records such as the *Health Records Regulation* under the *School Act* .

A "local government body" is defined in section 1(1)(i) of the FOIP Act and includes a variety of entities including municipalities, Metis settlements and the management bodies, housing authorities and foundations under the *Alberta Housing Act*. The latter category includes lodges. Lodges provide a wide variety of housing or accommodation and varying levels of support services including health care.

A "health care body" is defined in section 1(1)(g) of the FOIP Act and includes hospital boards, nursing home operators, provincial health boards, the Alberta Cancer Board, regional health authorities, community health councils and subsidiary health corporations. All of the health care bodies that are public bodies under the FOIP Act are also custodians under HIA.

Similarly, the Minister and Department of Health and Wellness ("AHW") are both public bodies under the FOIP Act and custodians under HIA. All of the designated custodians under HIA are public bodies under the FOIP Act. This means that organizational and personal information held by public bodies is governed by the FOIP Act. However, the personal information that falls within the definition of "health information" in HIA is carved out of FOIP and governed by HIA.

In practice, the entities that are both public bodies and custodians tend to have the same individual or group of administrative personnel responsible for implementing both the FOIP Act and HIA. This assists in creating internal expertise to coordinate privacy issues. Questions do arise about the interface of these two key pieces of privacy legislation as well as the application of other privacy provisions in specific fact situations (e.g., PIPA, PIPEDA, *Health Professions Act*, *Young Offenders Act* (this is the old but commonly recognized name), *Child Welfare Act*).

There have been difficulties in the flow of health information from HIA custodians to Government departmental areas. This difficulty has arisen because although health information flows readily amongst custodians who are subject to HIA rules and within the 'controlled arena', health information does not flow readily outside of this arena. Custodians can not disclose health information except as authorized by HIA. This sometimes means that custodians do not have the authority under HIA to disclose the amount of health information that Government departmental areas seek to collect without consent, for example for programs such as seniors benefits.

Health information under HIA is subject to more stringent privacy rules and custodian duties than personal information is under the FOIP Act. For example, HIA has explicit provisions for the protection of privacy such as requirements for mandatory Privacy Impact Assessments (PIAs), Personal Health Numbers (PHNs), express consent, research ethics review committee approval, data matching, information managers and transborder data flow. One of the downsides is that there is not a level playing field as there are more onerous requirements imposed on custodians and a higher level of protection for the health information of individuals under HIA.

However, on the whole in my view the current FOIP regime is working fairly well to protect the personal information including health information that is in the custody or control of Government Departments. In many instances those Departments are indirectly subject to HIA rules as custodians must impose those rules on affiliates and may impose those rules on recipients of health information. In other instances Government departments have chosen to implement privacy practices that exceed legislative requirements such as by voluntarily submitting PIAs.

Government departments have invested almost a decade of intensive effort to implement and fine tune the FOIP regime in their facilities. I see no compelling reason to impose the additional administrative burden of HIA on those public bodies.

Recommendation - HIA Section 1(1)(f): Maintain status quo for application to additional Government Departments and Local Public Bodies

2. HIA Section 1(1)(f): Maintain status quo for application to additional Public Sector Agents, Committees and Boards not already designated as Custodians

Schedule 1 of the *Freedom of Information and Protection of Privacy Regulation* (the "FOIP Regulation") lists agencies, boards, commissions, corporations, offices and other bodies that are public bodies, pursuant to the authority in section 1(1)(p)(ii) of the FOIP Act to designate public bodies.

For example, Children's Services provides extensive health services to children in their homes and in the community and operates various Appeal Panels, e.g., for the severely handicapped, child welfare and dependent adults, and the Social Care Facilities Review Committee. Community Development is responsible for the Human Rights and Citizenship Commission and for administering legislation such as the *Protection for Persons in Care Act*.

Human Resources and Employment is responsible for occupational health and safety, radiation health and the Workers Compensation Board and Appeals Commission. Infrastructure operates the Alberta Motor Transport Board and the Driver Control Board. Justice administers the Criminal Injuries Appeal Board, Fatality Review Board and Victims of Crime Programs Committee. Learning administers the Special Needs Tribunal.

Some AHW panels, committees, boards and individuals have been designated as custodians in section 2 of the *Health Information Regulation* under the authority of section 1(1)(f)(xiv) of the Act. The designated AHW entities under HIA are the Mental Health Review Panels, Mental Health Patient Advocate, MS Drug Review Panel, Out-of-Country Health Services Appeal Panel and Committee, Hospital Privileges Appeal Board, Billing Practice Advisory Committee and the Alberta Aids to Daily Living Benefits and Extended Health Benefits Appeal Panels.

These above designated entities have extensive amounts of extremely sensitive health information in their custody and control. However, other AHW entities with equally sensitive information about health are not designated custodians under HIA. For example, AHW entities such as the Alberta Alcohol and Drug Abuse Commission ("AADAC"), Alberta Health Facilities Review Committee, Persons with Developmental Disabilities ("PDD") boards and Public Health

Appeal Board are designated as public bodies under the FOIP Act but not as custodians under HIA.

Although HIA creates the authority to designate custodians by regulation, this designation goes to the scope of the Act. The scope of the Act directly affects the rights and entitlements of individuals under HIA. To the extent possible, decisions of this significance should be entrenched as a matter of statute rather than regulation as entities could be readily added or omitted by regulation without any requirement for public consultation.

Therefore, in my view the committee should consider whether the AHW entities that have been designated as custodians under the HIA Regulation for three years should now be included in the list of custodians under the Act. Although I am not making any specific recommendations about particular entities, in my view the committee should carefully consider whether the information about health that is held by other Government entities should be governed by HIA, either by the Act or Regulation.

Recommendation - HIA Section 1(1)(f): Maintain status quo for application to additional Public Sector Agents, Committees and Boards not already designated as Custodians

3. HIA Section 1(1)(f): Amend definition of a "Custodian" to include corporate entities

This review must specifically address the application of HIA to the information about health that is in the custody or control of any entity that is not a custodian (s. 109(2)(c)).

In my view, the definition of a custodian should be amended to include corporate entities such as medical clinics, medi-centres and Local Primary Care Initiatives ("LPCI's"). In practice these types of corporate entities may have the physical ownership, custody and control and the day-to-day responsibility for managing the health information that is compiled by custodians such as physicians working in these settings.

The current definition creates confusion as it is not clear whether or how HIA applies to these types of corporate entities. This change would be consistent with the approach taken with other corporate health care entities with responsibility for health information that are already explicitly included as custodians in HIA such as pharmacies.

Recommendation - HIA Section 1(1)(f): Amend definition of a "Custodian" to include corporate entities

4. HIA Section 1(1)(f): Amend definition of a "Custodian" when ceasing to practice to avoid 'orphan records'

Over the past three years, the office has been apprised of various situations of "orphan records", which arise when a custodian is no longer a custodian. For example, a health services provider such as a doctor may sell a medical practice, go into bankruptcy, retire out of the jurisdiction, cease to practice, lose mental capacity or pass away. These events may occur suddenly and without warning.

In most instances professional codes of ethics and professional regulatory guidelines have worked in tandem with HIA. Often existing approaches have been successful to ensure that health providers take measures to safeguard health information even after they have ceased to practice.

However, this is not always the case and at times health records are abandoned. Health information may be left in the hands of non-custodians such as family members, the community or a landlord. The result is that individuals lose their rights and protections under HIA. Individuals may not be able to locate their health records and consequently can no longer exercise rights such as access, correction or amendment. The privacy of the health information may not be sufficiently protected. Even the best efforts of non-custodians are not likely to be in accordance with HIA standards.

The additional difficulty is that when a custodian is no longer a custodian as defined in HIA, such as when a health professional is no longer licensed to practice, the traditional sanctions no longer apply. The entities that usually exercise oversight functions such as health professional colleges and the Commissioner have no continuing authority over the provider and hence no continuing jurisdiction over the health information.

In some instances health professional colleges have taken over and discharged the responsibilities of the practitioner who ceased to be a custodian in an attempt to protect the public. However, this approach has been problematic. The intervention of the professional colleges may encourage other custodians to fail to take protective measures, particularly in view of the administrative burden involved. Colleges may not have any legal authority to seize property such as health records, as they do not have similar legislation to the legal profession for custodianship of records of members.

Increasing privatization and marketplace forces that involve health information moving around from entity to entity, mean that this type of problem will likely become much more pervasive. This problem arises with individuals and particularly with private entities that may completely cease to exist or with corporate reorganizations that do not make provision for the health information. This has not been a problem with public bodies such as large government organizations as there is usually continuity of function and responsibility even when programs or operations are transferred. However, this is a particular problem with small organizations and with individual custodians.

There are various approaches that would assist to address these types of situations. This could be done by amending the definition of a custodian so that an individual does not cease to be a custodian until the health information has been appropriately transferred to another custodian or until appropriate arrangements have been made such as with an Information Manager. The Ontario health legislation has introduced such an initiative but with a more limited application.

I recommend that the definition of a custodian be amended under HIA to ensure that continuing responsibility for health information rests with a custodian who ceases to practice (and hence with their estate through their legal or personal representative).

Recommendation - HIA Section 1(1)(f): Amend definition of a "Custodian" when ceasing to practice to avoid 'orphan records'

5. HIA Section 1(1)(f)(ix): Amend definition of when a health services provider becomes a custodian so not limited only to providers paid by the AHCIP

A health services provider only becomes a custodian of health information under HIA when the provider is paid under the Alberta Health Care Insurance Plan ("AHCIP") to provide health services (s. 1(1)(f)(ix)). This means that individual rights and HIA custodian obligations for health service providers such as physicians currently only arise when the provider is paid by the AHCIP.

Health service providers such as physicians have multiple relationships with individuals and health facilities. The same provider may be paid in various ways for example as an employee, a contractor, a researcher, a student, a volunteer, an agent, an administrator, via hospital or facility privileges or via joint appointments at health and academic institutions.

The HIA approach is becoming increasingly problematic with the intertwining of private and public partnerships in the financing and delivery of health services. A physician clearly falls under HIA as an affiliate when providing services through a regional health authority but not necessarily when providing the same service through the WCB, a LPCI, a private hospital or through a private clinic such as the Gimble Eye Clinic.

This approach has created much confusion and uncertainty about the application of HIA, particularly with recent complex and creative funding initiatives. Innovative approaches to payment of health providers have resulted in much variability and multiple possibilities even within the same care setting.

The current approach that hinges on payment by the AHCIP creates significant concerns with the trend towards combined repositories of health information such as registries, databases and electronic health records where some of the information would fall under the Act but other information would not.

The application of health legislation in other Canadian jurisdictions such as in Manitoba, Saskatchewan and Ontario does not turn on payment. In my view it is not logical that individual health information rights such as access and privacy should arise and disappear with the provider's source of funding. Rights should not turn on whether the service is paid for by the AHCIP, the Department of Health and Wellness, First Nations/Health Canada, Corrections Canada, Veterans Affairs, private insurers or the individual.

I recommend that the definition of when health services providers become custodians be amended to eliminate reference to funding source.

Recommendation - HIA Section 1(1)(f)(ix): Amend definition of when a health services provider becomes a custodian so not limited only to providers paid by the AHCIP

6. HIA Section 1(1)(i): Amend the definition of "Diagnostic, Treatment and Care Information" to include genetic information

The definition of "diagnostic, treatment and care information" in HIA does not expressly include genetic information. Over the past three years there has been increasing concern and attention about the right of access and the protection of privacy of genetic information, which is evident in public opinion surveys.

Various surveys show that the public is becoming more aware of the significance of genetic information to the individual as well as to others such as ascendants

and descendants. The sensitivity of this information is obvious. Genetic testing such as DNA testing is readily available, often from private for-profit entities located out of the jurisdiction. The importance of protecting this type of information is evident due to the significance of the information on its own as well as increasing mandatory collection and the danger of secondary uses and function creep.

For example, DNA samples that are taken for purposes of paternity testing could be utilized for ulterior motives in the hands of a disgruntled ex-spouse. It is obvious that individuals could be harmed if genetic information gets into the wrong hands or as a consequence of the inappropriate collection or use or disclosure by custodians, researchers, law enforcement agencies, employers, financial institutions or insurance companies.

Some jurisdictions are taking a very targeted approach to similar types of information such as biometric information. For example in Australia, the draft Privacy Code of the Biometrics Institute proposes extensive safeguards for biometric information including mandatory Third Party auditing, mandatory encryption and destruction of original information.

The issue of genetic information arose in the last legislative review of the FOIP Act in Alberta. As a result of the recommendations made by that review committee, the definition of "personal information" was amended to include the individual's fingerprints, other biometric information, blood type, genetic information and inheritable characteristics.

In my view, the definition of "diagnostic, treatment and care information" should be amended to include genetic information in HIA. This amendment would go towards ensuring internal consistency within HIA as this type of information is contemplated elsewhere, for example section 35(1)(o) of the Act authorizes the disclosure of information to a descendant of a deceased individual.

The HIA definition should explicitly include genetic information to ensure that the same rules exist for access, correction and amendment as well as for the protection of privacy as for other types of health information.

Recommendation - HIA Section 1(1)(i): Amend the definition of "Diagnostic, Treatment and Care Information" to include genetic information

7. HIA Section 1(1)(m)(i): Amend definition of a "health service" so not limited to services paid for by the Department

The definition of a "health service" under HIA requires that the service be "directly or indirectly or fully or partially paid for by the Department" of Alberta Health and Wellness (section 1(1)(m)(i)).

As discussed earlier, this means that the existence of individual rights and custodian obligations under HIA currently turns on payment and arises only when the Department pays for the service. This approach has created much confusion and uncertainty about the application of HIA, as the Department may pay up to a certain level of service, may pay in particular circumstances or may pay up front and then receive reimbursement.

Further rationale for this recommendation was described earlier under point 5. and will not be repeated herein. I recommend that the definition of a "health service" be amended to eliminate reference to funding source.

Recommendation - HIA Section 1(1)(m)(i): Amend definition of a "health service" so not limited to services paid for by the Department

B. Disclosure of Health Information (Part 5)

1. HIA Section 35(1)(q): Amend the provision to include a Custodian who remains a Custodian but transfers health records

This recommendation is related to the corollary issue that was discussed above, which is the definition of a custodian and when that custodian ceases to be a custodian. These two recommendations are discussed separately as the recommendations are being made in chronological order as the provisions appear in the Act.

Section 35(1)(q) of HIA authorizes a custodian to transfer health records to a successor as a result of the custodian ceasing to be a custodian and when the successor is a custodian. This provision appears to preclude a custodian from transferring health records to a non-custodian and when a custodian is continuing to be a custodian.

In practice, a custodian might continue to be a custodian but still need to transfer health records. For example, a regional health authority may transfer an entire program or service or the boundaries of the region may change so health records may need to be transferred to a successor custodian. Similarly, providers such as physicians may decide to change their geographic location or area of practice and expertise and may need to transfer health records to a successor custodian.

In situations where a custodian is ceasing to practice, there might not be another custodian interested in taking over custody and control of the health records. This is particularly the case due to the administrative burden involved and the current shortage of some types of health providers such as general practitioners in Alberta. A logical solution for a custodian who is ceasing to practice or for the estate of a deceased custodian might be to transfer the health records to a non-custodian such as a professional record storage company. Section 35(1)(q) appears to preclude these types of arrangements for health records.

I have attempted to address this issue in an Order that involved a ministerial change in the responsibilities of the Alberta Mental Health Board and the regional health authorities. In that situation, the Alberta Mental Health Board was no longer going to be providing certain mental health services to individuals and the board was transferring the records to the regions. The board that transferred the records at issue did continue to exist as a custodian, albeit with different responsibilities.

In that Order, I found that a custodian could continue to be a custodian in one capacity while ceasing to be a custodian in another respect. Although I attempted to provide a practical solution, the custodian still had to undergo an inquiry to settle this particular complaint, which arose due to the expectations created by the wording of the provision. I provide this scenario merely as an example of the confusion this provision has created and the difficulty that exists for custodians who are attempting to take appropriate safeguards for protecting the privacy of health information. In my view, section 35(1)(q) of the Act should be amended to enable the custodian to transfer records and should not be restricted to situations where that custodian is ceasing to be a custodian.

Additionally, the custodian should not be precluded from transferring health records to a non-custodian. In order to ensure that the information continues to receive HIA protection, I recommend that the custodian who is transferring records to a non-custodian be required at minimum to impose HIA obligations upon the recipient. Examples of the types of requirements that could be imposed exist in other HIA provisions such as agreements with information managers (s. 66), agreements with researchers (s. 54) and for recipients outside of Alberta (HIA Regulation, s. 8(4)).

The practical difficulty with this approach is that with all of these HIA arrangements the custodian remains ultimately responsible. However, the custodian who is ceasing to be a custodian is trying to get out of the administrative aspects involved in the custody and control of health information. However, in my view this is still a preferable approach to a legislative provision

that appears to preclude a custodian from making reasonable arrangements for safeguarding health information.

Recommendation - HIA Section 35(1)(q): Amend the provision to include a Custodian who remains a Custodian but transfers health records

2. HIA Section 50: Amend the provision to create explicit authority for the Commissioner to publish a summary of approved research projects

When approving a research proposal, HIA requires ethics committees to prepare a response as outlined in the Act and to send a copy of the response to the Commissioner (s. 50(3)). HIA is silent about the authority of the Commissioner to publish this type of information. The Act authorizes me to disclose copies of an Order in particular circumstances (ss. 80(5)(6)). However, other parts of the Act impose an onerous duty of confidentiality (s. 91). It is unclear whether or not I am authorized to publish research approvals in a research registry on the Website.

In my view, it is in the interests of openness and accountability to initiate a research registry on our Website for research approvals that have been granted by the designated ethics committees. Some of the ethics committees already post this type of information on their own Websites about the research approvals they have granted.

This initiative would provide more information to the public and could be similar to the PIA registry that has been successfully posted on our Website, using summaries provided by the custodians with accepted PIAs. The Manitoba Ombudsman is recommending greater openness in this area in Manitoba under their health information legislation and has suggested that approved research projects be published in their annual report.

I recommend that HIA be amended to provide explicit authority for the Commissioner to publish a summary of approved research projects.

Recommendation - HIA Section 50: Amend the provision to create explicit authority for the Commissioner to publish a summary of approved research projects

C. Commissioner Powers (Part 7, Division 3)

1. HIA Section 84: Establish an explicit auditing power that expressly authorizes the Commissioner to conduct audits

In addition to specific powers, HIA establishes general powers and duties for the Commissioner to monitor how the Act is administered and to ensure that its purposes are achieved (s. 84). These general powers include an explicit power of investigation including independent investigation to ensure compliance with HIA (s. 84(a)). The Commissioner is authorized to engage in or commission "a study" of anything affecting the achievement of the purposes of the Act (s. 84(e)) and to comment on PIAs (s. 84(f)) and data matching (s. 84(g)).

It could be argued that the Commissioner already has the authority under HIA to conduct audits by virtue of these types of provisions. However, none of these powers explicitly authorize the Commissioner to conduct audits or to compel the information needed to complete the audit.

This approach is in contrast to other privacy legislation such as PIPEDA, which contains a specific provision that expressly creates the authority for the federal Commissioner to conduct an audit. Similarly, an express audit power exists under the federal *Privacy Act* in Australia.

An explicit legislative auditing power for the Commissioner is a powerful tool to ensure that custodians are safeguarding the privacy of health information. However, the exercise of this power may be contentious. For example, there may significant consequences for the custodian or entity being audited if they are determined to be in breach of HIA.

Due to the onerous nature and financial cost of conducting audits, particularly audits of electronic databases, it is likely that very few audits would actually be conducted. This could mean that whichever custodian or entity is selected for an audit might complain about being singled out and allege that there was bias involved in the decision to conduct the audit.

Explicit auditing power is important for reasons of clarity in the Act. The Commissioner should not have to face an avoidable challenge about jurisdiction to audit, should circumstances arise where the Commissioner believes that an audit should be conducted.

I recommend that the Act be amended to create a provision to provide for an explicit auditing power for the Commissioner, particularly for auditing electronic health record systems.

Recommendation - HIA Section 84: Establish an explicit auditing power that expressly authorizes the Commissioner to conduct audits

Summary of Recommendations

My ten recommendations are summarized as follows:

HIA Section 1(1)(f): Maintain status quo for application to additional Government Departments and Public Bodies

B. HIA Section 1(1)(f): Maintain status quo for application to additional Public Sector Agents, Committees and Boards not already designated as Custodians

C. HIA Section 1(1)(f): Amend definition of a "Custodian" to include corporate entities

D. HIA Section 1(1)(f): Amend definition of a "Custodian" when ceasing to practice to avoid 'orphan records'

E. HIA Section 1(1)(f)(ix): Amend the provision for when a health services provider is a Custodian so HIA applies to providers regardless of how providers are paid

F. HIA Section 1(1)(i): Amend the definition of "Diagnostic, Treatment and Care Information" to include genetic information

G. HIA Section 1(1)(m)(i): Amend definition of a "health service" so not limited to a service funded by the Department

H. HIA Section 35(1)(q): Amend the provision to include a Custodian who remains a Custodian but transfers health records

I. HIA Section 50: Amend the provision to create explicit authority for the Commissioner to publish a summary of approved research projects

J. HIA Section 84: Establish an explicit audit power that expressly authorizes the Commissioner to conduct audits